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AUTHOR Scharlach, Andrew E.
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ABSTRACT

This guide was designed to help individuals interested in developing caregiver support groups. It begins with an overview of the caregiving situation, identifying stresses associated with caregiving and factors which have been shown to moderate stress. Purposes of a support group are discussed; differences between support and therapy groups are explained; and structural aspects of support groups are described, including the format of the group, group membership, open or closed membership groups, time-limiting, and group size. The role of leading a support group is discussed. Three developmental stages of groups are identified: orientation, evaluation, and action. Outreach, internal communications, sponsorship, leadership training, and evaluation are discussed as they relate to group maintenance. Seven topics are addressed in the final section on pitfalls and special issues: (1) member burnout; (2) leader burnout; (3) resources; (4) new members; (5) social functions; (6) controlling members; and (7) social action. The guide concludes by stating that support groups can assist their members to achieve personal and group goals related to increased feelings of competence and effectiveness in the caregiving role. (NB)

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ORGANIZING AND LEADING CAREGIVER SUPPORT GROUPS

Andrew E. Scharlach

Stanford University

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THE CAREGIVING SITUATION

The Strains of Caring

Contrary to popular thinking, the great majority of impaired older adults live not in nursing homes, but in the community, managing as best they can in an extremely difficult situation. As Elaine Brody and others have documented, family assistance often makes the critical difference which allows these elders to remain in their familiar surroundings. In fact, family members provide approximately 80% of all home health care for disabled adults.

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The reasons why families are so willing to assist their impaired loved ones are certainly as various as the unique situations and past histories of the families themselves. For some, empathy with a loved one, or the desire to maintain a maximum amount of continued contact, is paramount. These are, perhaps, the lucky ones, for they can be expected to derive some actual enjoyment out of their caregiving behavior.

The format and most of the information included in this report is derived from a workshop, "Supportive Programs for Caregivers of the Elderly", help on October 16, 1982, at Health Center 5 in San Francisco, CA. Presenters were Kathy Keefe, Cecilia London, Carole van Aelstyn and Kathy Kelly.

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Some are motivated primarily by a feeling of duty, prompted by internalized societal norms regarding the proper behavior of a "good wife"[1] or "good child". Others are motivated by a sense of fairness, and feel obligated to repay a parent or spouse for kindnesses s/he had previously bestowed on them. Still others feel the acute pressure applied by family and friends, who "expect" them to step in when needed, for whatever historical or personal reasons. The more her behavior is motivated by feelings of obligation, and the less by a sense of enjoyment, the more burden the caregiver is liable to feel, and the more difficult will it be for her to maintain her caregiving activity in the face of mounting stresses.

Recent research has attempted to identify the aspects of caregiving which generally prove to be the most stressful. One of the most frequently mentioned and most severe is the frustration which comes from devoting so much time to caregiving that other important activities are neglected. Inevitably, the person experiences the "role conflict" of competing personal priorities, with their mutually exclusive demands on time, energy, money and other resources. Silverstone & Hyman (1982, p.12) have described the feelings of a middle-aged woman caught in such a conflict:

> WHAT'S HAPPENED TO ME? I'm like the rope in a tug of war between my parents and my children. I always seem to be needed in two places at the same time and I'm never in the right one. When I'm with my parents I'm always asking myself, "What am I doing here? I ought to be with my children." And when I'm with my children I'm always asking myself, "What am I doing here? How can I leave my old parents alone so much?" It's awful to feel so guilty all the time. But do you know there's something even worse? It's that little voice inside my head that's always crying out, "What about me? When is there going to be time for me? Doesn't anybody care?"

Perhaps equally stressful, although less researched, is the "role fatigue" which develops when one must perform a set of activities which contain relatively little potential for feelings of personal pleasure or accomplishment. People are able to tolerate a

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[1] In the text, caregivers will be considered to be female family members. This assumption reflects literary convenience, as well as the typical (and perhaps prototypic) caregiving situation.

great deal of discomfort and personal sacrifice, if they believe that they will ultimately reach some valued goal. However, for the caregiver, the only goal is the prevention of institutionalization, the behavior required is poorly defined and not always within the caregiver's ability, and failure (whether because of placement or death) is inevitable. It is no wonder, then, that caregivers get "burned-out", with an apparently high rate of depression, frustration and feelings of hopelessness.

In addition, caregivers typically experience all the distress of watching a loved one decline, magnified by the fact that the caregiver's frequent contact makes the decline seem especially poignant. There is liable to be the grief that always accompanies loss, anticipated as well as real. An often overlooked aspect of this is the emptiness in the person's life when a parent or spouse, although still living, cannot fulfill the role in which they are needed. This is particularly difficult for the spouse, who must bury emotional needs which the impaired person can no longer meet, and who is precluded by societal norms from seeking alternative sources of emotional gratification.

All of these stressors take their toll on the caregiver. No matter how much she may love the disabled family member, and want what's best for them, the caregiver is likely to feel anger -- at the patient for being ill, at other family members for not doing their share, at the health care system for its inadequacies, and at herself for "not doing enough" (seldom recognizing that no one can do enough, if "enough" is defined as returning the patient to optimum functioning). At the same time, she will probably feel guilty -- for not adequately fulfilling the caregiving role, as well as for her anger towards the patient. It is no wonder that cargivers have been reported to have an increased vulnerability to mental and physical impairment, as well as perhaps an increased likelihood of death.

In the midst of such emotional trials, the caregiver is called upon to adopt new and unfamiliar roles, many of which would be difficult under the best of conditions. Women who had been kept ignorant of financial and other matters of vital importance must often assume total responsibility for all decisions about the family's economic well-being, at a time when financial problems abound. Others must learn to drive a car for the first time. Almost all must negotiate the frustrating mazes of society's bureaucratic social service systems. And, at the same time, they must cope with the anger and frustration of a spouse or parent whose role is being coopted, who is experiencing the steady spiral of increased dependency and personal devaluation.

Moderating Factors

A variety of factors have been identified as potential moderators of the stresses identified above. For example, the current caregiving situation must be understood in the context of the ongoing relationship of the individuals involved. A caregiver who has always enjoyed the patient, who has found personal satisfaction in their interaction, will be more likely to find pleasure in the opportunity to provide assistance, and the recipient will experience less conflict in receiving it. Similarly, a patient who has always been a likeable and accepting person will be much easier to get along with than one who has tended to respond to frustration with anger, bitterness or unreasonable demands on loved ones.

The existence of a good informal social support network will also play a part in buffering the caregiver against stress. Research suggests that the presence of a confidante, someone who understands what one is going through, may be the single most important protection against depression for caregivers. Other evidence suggests that it is not so much the actual amount of contact with family and friends which is most important, but whether the contact that does occur is of satisfactory quality.

My own research with spouse caregivers indicates that utilization of home health and homemaker services provides the greatest relief from the burdens of ongoing caregiving. We have also found extended respite care to have a large impact on relieving caregiver strain. Other studies have implicated daycare, day respite, in-home respite, and other formal support services. Information and referral services are a vital, albeit largely overlooked, factor in the ability of caregivers to obtain assistance which is best suited to their situation. In addition, the family's financial situation is often a major factor in determining whether they can arrange for needed assistance, and in legitimizing whatever outside assistance is obtained.

Last of all, the caregiver's typical coping style plays an important part in determining how she will respond to the various stresses we have identified. Among the factors which have been identified as helping a person cope more successfully are the following: prior successful experience with caregiving (or even carereceiving), prior successful experience with illness or loss, a history of independent decision-making, the ability to alter existing expectations to fit unexpected events, proven flexibility in the face of novel situations (including the ability to be less perfectionistic in situations where "adequate" is the best one can hope for).

ORGANIZING A SUPPORT GROUP

Purposes of a support group

Although support groups for caregivers can assume many different forms, they are generally oriented around a number of common objectives. The manner in which such objectives are prioritized and implemented will determine structural features of the group, which types of issues will be discussed, as well as how members are most likely to

interact with one another. Among the objectives most frequently identified are the following:

1) Assess personal attitudes concerning caregiving responsibilities. This objective rests on the assumption that among the leading factors in caregiver distress are feelings of guilt and resentment which stem from unrealistic expectations regarding one's caregiving behavior. If caregivers expect themselves to return their loved ones to previous levels of functioning, or stem the disease process, or meet the patient's every need, they are likely to be setting themselves up for failure, and feelings of guilt. Moreover, the super-human effort which such caregivers may exert on behalf of their patient is likely to interfere with other responsibilities and personal needs they themselves may have, making the caregiver vulnerable to feelings of resentment or even anger at the patient for "robbing them of their time".

2) Confront the limitations of the caregiving role. As caregivers begin to clarify their own feelings concerning their caregiving responsibilities, they realize that there are limits to how much they can do for their patient, and that there is a point beyond which the benefit to the patient is outweighed by the cost to themselves. As part of this process of clarification of costs and benefits, caregivers also realize that there may be real limits on the degree to which their loved one will be able to resume previous levels of functioning. Even their most concerted efforts may be quite insufficient to propvide the results they would prefer to see. Caregivers may go through a period of mourning, for the loss of their loved one's previous level of functioning, for the loss of some of their own expectations, and for the loss of their fantasied ability to protect their loved one against illness and decline.

3) Forgive, if not forget, past injustices. Every human relationship is fraught with unresolved conflicts stemming from hurt feelings based on earlier injustices (both real and imagined). For individuals to be most helpful to one another in the present,

such feewlings from the past must often be overlooked. This is particularly true when the supposed perpetrator of the injustice is now dependent on others for assistance. Often, feelings dating back to childhood cloud a caregiver's ability to think clearly about her patient's needs in the present.

4) Identify the most realistic action plan, based on one's own capabilities and resources. Problem-solving techniques are most often utilized to help participants to think clearly about the problems they face, too identify the needs which exist and their realistic ability to respond, and to weigh the various alternative strategies which may be available for meeting those needs. This is usually an ongoing process, involving numerous revisions in light of the success or failure of various aspects of an initial plan.

Self-help and support groups are particularly well-suited for meeting these goals. Support groups provide a safe environment, wherein individuals who share a common predicament can offer mutual concern and acceptance to one another. Because the emphasis is on the supportive aspects of the group rather than changing the objective reality with which members must cope, such groups fit well with the demands of a situation which is chronic, ongoing, and from which there may be little apparent escape. Instead of attempting to change the problem in significant ways, participants are often encouraged to seek changes in their own ways of handling the problem, in their utilization of available resources, and in their own reaction to the situation.

Support groups offer the opportunity to learn from one another about effective coping strategies and concrete skills, which can result in increased feelings of self-efficacy and improved self-esteem. At the same time, members often gain better understanding of the problem situation and their reaction to it, and are able to shift reference norms from unrealistic personal ones to more moderate norms, due to the normalizing effects of group comparison processes.

Differences between support and therapy groups

Perhaps the major difference between support groups and therapy groups is the former's heavy emphasis on peer support and deemphasis of the leader role. Structurally, this peer emphasis is displayed by the absence of fees charged for services in most of these groups, as well as in the individual and group responsibility for maintenance and continuation of the group. Members may be expected to contact absent members, to provide refreshments for the group, and to recruit new members. The focus is usually on networking within and without the group meetings, rather than maintaining the clearly delineated participant roles of most therapy groups.

Support groups generally reject a traditional "medical" model of acute illness and treatment, preferring a "holistic" model which emphasizes wellness and coping in the face of chronic difficulties. Borrowing heavily from the human potential movement, support groups rest on underlying assumptions that individuals harbor the latent ability to tolerate and learn from even the most difficult of situations. The purpose of the group experience is to activate and reinforce this potential for effective coping behaviors. To this end, participants help one another to identify obstacles to effective and growth-stimulating coping techniques, and work together to develop appropriate problem-solving plans and evaluate the results.

Unlike many types of therapy groups, such support groups focus primarily on current aspects of feelings and behavior, rather on the historical roots of current conflicts. Rather than attempting to understand and resolve longstanding concerns which may be fueling present problems, there is a tacit assumption that historical causes are tangential to the problem-solving process, and may actually interfere with movement towards future-oriented behavior or attitude change.

Only the most radical of support group theorists would argue that therapy groups are unnecessary, however. In fact, many support group leaders are quick to exclude any potential or present member who displays the need for a more directive group experience. Among the common indicators for referral to a therapy group are the following: 1) the presence of acute psychosis, or the potential that it may develop if the individual experiences pressure to alter her current pattern of coping; 2) inappropriate behavior, often based on emotional inadequacy or neediness, which interferes with the group process; 3) psychological depression which is so severe as to make heavy emotional demands on other members without adequate reciprocation; 4) the presence of an acute, rapidly changing, stressful situation, which requires a speedy response and the interruption of developing psychosocial breakdown processes.

Structural aspects of support groups

1) The format of the group can be either totally discussion or a combination of discussion and education. The latter format, typified by "family life education" groups, places greater emphasis on the leader as expert, on whom members can rely for information and resources. The leader's presentation serves to stimulate member interaction and also to resolve differences of opinion. Groups with strictly a discussion format emphasize the interdependence of all members, and tacitly discourages dependency on any one "authority figure". Moreover, members are forced to confront unrealistic expectations about having someone or something magically improve their situation; in so doing, they may improve their ability to assume greater independent responsibility for their own psychological well-being. However, such heavy demands on individual responsibility may be too great for the more stressed members, leading to greater drop-out rates in more discussion-oriented groups, either because of insufficient psychological investment in the group process or because of dissatisfaction with the benefits received when compared to the investment made.

2) Membership may be quite limited or all-encompassing, depending on the goals and client population of the group. In some cases, it is most appropriate to limit membership to one specific population, such as spouses of elderly Alzheimers' patients; while, in other cases, it may be perfectly reasonable to include any or all of the following classes: children, siblings, parents, friends, professionals, hired caregivers, etc.

3) In addition, membership may be open or closed throughout the life of the group. Open membership groups have the benefit of being available to persons during periods of crisis, without the heavy demand for regular group involvement once the crisis has passed. For many individuals, this provides a relatively "pain-less" means of becoming gradually more and more involved over a period of time, rather than having to make a serious commitment prior to evaluating the costs and benefits of group membership. However, for many individuals, such groups provide an excuse to make only minimal investment in changing their response patterns, and the same person may come back numerous times over a period of many months, always manifesting the same concerns but never able to proceed very far in resolving those concerns. Moreover, for those stalwarts who do attend regularly, the continual orientation of new members and repetition of previously-discussed issues can become quite boring, leading to member apathy, even in those situations where individuals continue to attend because of past benefits and force of habit.

Groups with a closed membership from the very beginning are more likely to quickly develop a close-knit sense of interpersonal intimacy and group identification. As a result, they tend to traverse the various stages of group development, while open groups seldom get beyond the stage of pre-affiliation. At the same time, the pressure on individual members can be quite intense from early on, and is likely to exclude persons who are unable or unwilling to handle that kind of intimacy in this area of their lives. For individuals who feel constrained already by the hefty responsibilities of the

caregiving role, these added commitments may be overwhelming. Some groups have tried to strike a balance between open and closed membership by allowing interested persons to attend a few meetings before making a commitment to the group, after which time ongoing active participation is required of members if they wish to continue their membership in the group.

4) A related structural issue concerns whether a group will be time-limited or open-ended. Time-limited groups are more likely to assume an active, problem-solving approach from the very beginning, with clearly-defined limits on the range and depth of topics to be considered. Members are forced to take responsibility for setting priorities and for working together to meet their goals. Because time is limited, digressions into consideration of tangential issues is discouraged and a clearer focus is maintained. Moreover, in a very real way, individuals observe that the problems are considerably more complex than any finite amount of time. Progress is easier to evaluate, and individuals are considered to be more autonomous and personally potent than in many open-ended groups.

In open-ended groups, problems can be discussed in considerably more depth and breadth, with the opportunity to explore a particular, common concern in all of its most important aspects. However, this very availability of time can lull participants into thinking that they need not work as intensely towards active solution of their concerns. Moreover, the frequent lack of clearly-explicated goals can alienate individuals who benefit from a reliable sense of group structure, and want to know that they have a legitimate way to end their involvement in the group's development.

One interesting way to resolve some of the differences between open-ended and time-limited groups is to have an explicit time contract, which is then renewable upon completion. For example, a group might decide to meet for ten weeks to discuss specific issues, at which time it would evaluate its progress and decide whether any or all of the

members would wish to continue for another ten weeks with the same or different objectives. If desired, new members can be included prior to the start of the next round. If participants really do feel free to come and go every ten weeks, but only at that time, many of the benefits of both open-ended and time-limited groups can be gained.

5) The size of the group will be limited by the group's goals, by the population being served, and by the resources available. Frequency varies greatly, with most groups meeting once a week. It is quite difficult to maintain a sense of group trust and intimacy among members who only see each other once a month or less, and this should be kept in consideration by group leaders who fear that more frequent meetings will be too demanding for participants. In general, it is probably better to meet too often than not often enough. Time of day depends on the availability of the target population. Most often, lower and upper SES women are available during the day, while middle SES women are more likely to work full-time and be available in the evening. Older adults are also more likely to be available during the day, particularly in the late morning.

The location of the meetings is usually best if held in a well-known building, preferably near restaurants and shopping. Where possible, utilize a setting which houses services to which many target individuals are already linked. A good possibility is an established health-related organization or service, which may possess considerably greater visibility and respectability than a free-standing psychosocial program. Even where such a linkage is not feasible, it may be beneficial to provide a needed concrete service as a first step in making contact with potential group members, since people often require a socially acceptable "reason" for coming for help (the need for tangible assistance is generally considered to be more legitimate in our society than the need for relief from intolerable stress). Stability is quite important, and so meetings should not be rotated except when unavoidable. Of course, certain classes of participants will require special consideration. For example, elderly individuals may need access ramps,

rooms with minimal ambient noise to distract them, good lighting, etc.

LEADING A SUPPORT GROUP

The Leader's Role

Probably the most effective role for a support group leader to assume is that of group facilitator and consultant, rather than the more parental role traditionally played by psychodynamically-oriented group therapists. Caregivers benefit from leadership which emphasizes their strengths, rather than highlighting their weaknesses. The leader's behavior should indicate that participants are regarded as strong, capable individuals, with relatively good coping skills, who are managing the best they can in the face of a difficult situation. In effect, the participants themselves are regarded as experts, with the leader being present to help them refine their existing skills, share with one another in the most appropriate and supportive manner, and utilize their abilities in the most effective way possible.

At first, the leader will usually need to educate members regarding the purposes and functioning of support groups, which may be a new experience for many members. Individuals are usually more accustomed to task-oriented groups such as committees, or else social groups. Emotional sharing is often limited to family and friends. Thus, the thought of sharing personal concerns and highly emotional experiences with a group of strangers may be quite threatening, and the leader may have to help facilitate this process. Generally, this is done by outlining the leader's expectations regarding group process, by emphasizing confidentiality, by asking members to share their personal thoughts and feelings about their concerns, and by modeling appropriate expression of and response to feeling statements. Often the leader will need to monitor initial expressions of feeling to make sure that neither too little nor too much feeling is being expressed

during the early stages of the group's existence. Too little feeling can reinforce the image of feelings as frightening and something to be avoided. Too great an expression of feeling too early on can make it difficult for members to be sure that their emotions won't become overwhelming. The leader moderates a middle ground for the group.

In general, most leaders assume a non-directive (Rogerian) style, helping participants to clarify their own and one another's personal concerns, and facilitating the development of supportive and growth-enhancing interpersonal interactions. In addition, some leaders serve as resource persons, providing information regarding services available in the community and even at times linking participants to those services. Leaders may also serve as experts on issues relevant to group members, teaching about the physiology or psychology of aging, for example. Other leaders may wish to alter members attitudes regarding their caregiving responsibilities, perhaps emphasizing that caregivers should not expect themselves to fulfill unreasonable demands that others or they themselves may place on them, and that care-provision may better be understood as a societal problem rather than a personal one.

As the group's facilitator, the leader takes responsibility for promoting the ongoing stability of the group. Usually, the leader will arrange for a meeting site and maintain its suitability and availability. S/he will advise participants of future meetings and assist individuals to attend, by arranging transportation when necessary, for example. S/he will make certain that absent members are contacted and their needs made known to others. S/he will also help the group to remember and mark members' birthdays, illnesses, deaths, etc.

In order to assist the group and its members to more fully individuate as responsible, self-efficacious persons, the leader will also foster the development of indigenous leadership among group members. Usually, this occurs as the leader assists participants to take increased responsibility for the group process, based on the leader's initial

modeling of appropriate group interaction. Over a period of time, the leader may ask members to assume responsibility for structural aspects of group existence, such as contact with other members, finding out about community resources, etc. In some cases, this process may be facilitated by meeting separately with a small subgroup of core members, who can help other participants in much the same way that the leader had done previously. The leader's then takes more of a background role, shifting to the foreground only during times when the existing order is potentially threatened, as when numerous members miss meetings. In such cases, the leader essentially plans for her/his own obsolescence, a time when the group will no longer need professional assistance to facilitate its process. Some leaders feel that this can happen as quickly as a few months; however, the general consensus is that one or two years of group meetings are necessary before a group can truly be considered to be self-sufficient and able to respond effectivel to any changes from inside or out, without the assistance of a leader.

Developmental Stages of Groups

1. ORIENTATION. Initially, the leader acquaints participants with the general objectives and structure of the group, as discussed earlier in this paper. It is particularly important that individuals have a clear sense of what is expected of them, as well as what they can expect from the leader and one another. Even though they may be too anxious to think clearly about the initial "ground rules" during the first meeting, the fact that they are verbalized will lay an important foundation for later discussions. In addition, members are given the tacit assurance that it is permissible to participate in discussions of such meta-concerns as the structure and function of the group itself.

The first meeting is also the time for participants to find out about one another - what each person's concerns are, and what they want to gain from the group. This builds mutual understanding, while consolidating commitment and providing a rela-

tively non-threatening initial attempt at self-revelation.

Initial discussion is most often linked to the needs and problems of the "patient", rather than of the caregivers themselves. Many caregivers seek concrete information about their patient's needs and how to meet those needs, often hoping that their difficulties will be ended if they can just obtain the "right" information. Rather than interpreting these expectations as "magical", the leader is generally best advised to respond directly to questions and provide the information requested at an appropriate time. At the same time, it is helpful to remind participants that 1) there is no perfect solution to such complex problems; 2) if the solution were so simple, they would have found it themselves without needing the leader's input; and, 3) what works for one person may, or may not, work for someone else in a similar situation. Most important of all, the leader demonstrates a sincere concern and empathy for the strain that members feel, and which motivates their quest for solutions to their difficult problems.

2. EVALUATION. As participants begin to realize that the leader will not be able to provide magical solutions, and as they begin to trust one another more, feelings will increasingly come to the surface. At first, there may be a considerable amount of frustration expressed, often directed towards the leader for not being able to alleviate members' difficulties. At times, the frustation may take the form of passive resistance, marked by signs of depressed or withdrawn participation. It is important for the leader to recognize, although not necessarily interpret, that this behavior reflects anger which is displaced from 1) the impaired patient, who is both loved and hated, and towards whom it is unacceptable to be angry, 2) the health-care system, which the leader often represents and which is generally ill-equipped to handle the kinds of chronic situations with which caregivers must cope, 3) the caregivers themselves, who are unable to live up to their own expectations regarding their ability to perform the caregiving role without experiencing personal strain.

The process of sharing and clarification of feelings can be facilitated by assisting participants to use "I" statements, and by reinforcing the idea that all feelings are acceptable as topics of discussion, if members take responsibility for them as their own. In addition, "I" statements help concretize feelings, so that they do not become so vague and seemingly overwhelming. The leader may also effectively help members to take increased personal responsibility for finding their own solutions by splitting the group into smaller subgroups or cliques, made up of individuals who have similar concerns or situations. By emphasizing the importance of idea exchange, advice-giving and support among subgroup members, the focus of the group is shifted away from dependence on the leader, and members are enabled to meet specialized personal needs which may have gotten lost in the larger group process. Often, such cliques may wish to get together socially, which can be encouraged as long as subgroup ties are not allowed to significantly interfere with the interaction of the members when the larger group meets as a whole. Another technique is for the leader to ask members to summarize for the group another member's situation and what s/he wanted to get out of the group experience. This is another tool for decreasing dependence on the leader.

3. ACTION. To the extent that a support group is considered to be a problem-solving group, members will seek to alter either their current situation, or their perception of it, or their reactions to it. Within the context of a supportive and constructive group discussion, they can clarify their situation and their expectations, can evaluate possible options, can make initial attempts at producing change, and can implement a plan for making larger changes in their situation. One type of change concerns caregiving responsibilities. Most often, this involves the identification of available community resources for assuming some of the load of providing assistance, as well as the working-through of conflicting feelings regarding the utilization of such resources. Also, more effective techniques for caregiving (for example, learning how to handle incontinence

more easily), can be of great help. A second type of change may be sought with regard to expectations regarding how much help to provide an impaired loved one. This requires honest elaboration and critical evaluation of personal attitudes and needs, often of long-standing duration. In addition, it is usually helpful to make secondary alterations in how one interacts with others and particulary with the patient. A third type of change involves how the caregiver reacts to the strain of caregiving, and how s/he can better take care of her/himself. Stress management training has been utilized with some effect to achieve these goals.

The goals of actions such as these are the same as the goals of the support group itself, and may include one or more of the following: increased mastery and self-perceived self-efficacy, increased effective use of available resources, more realistic expectations regarding oneself and others, as well as decreased personal isolation and depression.

Group Maintenance

Like any vital organism, support groups require proper "care and feeding" if they are to resist breakdown ("burn-out"). Supportive functions such as those identified below are most often carried out by the leader at first, but can later be transfered to the group members themselves. However, professional leaders should be careful not to overburden already-stressed group members by shifting too much responsibility onto the lay leaders too early in the group's development.

1) OUTREACH. Public relations are important if potential new members are to be identified, and if the group is to develop and maintain credibility in the professional and lay communities. Among the most frequent types of outreach are direct mail announcements (flyers), presentations to other groups, and press releases to the media.

2) INTERNAL COMMUNICATIONS. Maintenance of contact among members is most important in more infrequent or open-ended groups, where cohesiveness may be a distinct difficulty. Newsletters are most effective if they are clearly structured and easy to read. They generally bear an identifying insignia for the group, and can include information about the members, advice, information about community resources and caregiving aids, and notices of upcoming meetings. Members can be involved directly in all aspects of production of the newsletter, such as collecting information for inclusion, writing, collating, mailing, etc. Post cards can be used to advise members of the time of the next meeting. However, a more effective tool is a "telephone tree", which not only involves more members in a minimal personal commitment to the group's existence, but also provides a forum for increased interpersonal sharing. At the same time, members may well share with one another reactions to the group process which they might resist sharing with the leader. In this way, developing problems or changing needs can be identified before they become a significant obstacle to group functioning.

3) SPONSORSHIP. It is usually helpful to have at least nominal support from an established agency. In this way, the group gains both credibility and legitimacy. Perhaps more importantly, it is reassuring to members to have institutional sanction for the group's continued existence, which reinforces the image of the group as stable and continuous, rather than a rather fragile entity which could dissolve at any time.

4) LEADERSHIP TRAINING. The development of indigenous leadership has been discussed previously. Without such development, any attempt by the professional leader to withdraw from active leadership is a likely prologue to the group's demise. Indigenous leaders will benefit from clearly-defined and sanctioned roles within which to exercise their developing leadership in the group hierarchy. They will need the leader's active cooperation and support, if they are to succeed in claiming specific, appropriate leadership roles within the existing group structure.

5) EVALUATION. To be most successful, any group must continually evaluate its progress towards meeting the needs of its members. Evaluation is rooted in clear criteria for success which have been explicitly identified by group members, usually from the first meeting of the group. Among the areas to be evaluated periodically are the following: the number of attendees, the number and types of programs offered within the context of the group, the amount of personal sharing and emotional intimacy among group members, group cohesiveness, whether all members share equally in group interaction, development of indigenous leadership, changes in the functioning of members when they are in the caregiving situation, as well as the group's ability to meet other personal goals of its members. Among the formats for evaluation are a simple quantitative summary of number and types of participants, a written evaluation by participants, or verbal feedback by and among the participants. The latter is most preferable, as it can foster the development of new, more appropriate group goals, and also suggest alterations in group process in light of those new goals.

Pitfalls and Special Issues

1. MEMBER BURN-OUT. Group members can become quite overwhelmed when they take on too much too soon. Their situations are already quite stressful, and many of them begin their participation in the group by feeling that they are at "the end of their rope." Too much responsibility too soon, or even too much sharing too soon, can prove frightening. It is better to help them to start slowly and develop a sense of clear limits and a supportive network which will assist them to emotionally handle increasing demands, which can eventually stimulate increased peronal and group growth.

2. LEADER BURN-OUT. Leaders can also become quite overwhelmed by taking on too much without enough ground-work and support. Support groups have traditionally been devalued by psychotherapists, leading their leaders to question their own

professional adequacy at times. In addition, there are few sources of support for the leader her/himself, as s/he attempts to asssist group members to struggle with highly emotional and personal issues. If the leader does not have a clear sense of her/his own needs, and areliable outside source of emotional support, both s/he and the entire group will suffer.

3. RESOURCES. Typically, there are few sources of financial support for self-help groups, other than the members themselves, who are often in difficult economic situations. Thus, a great deal of time and energy must often be devoted to clerical and other mundane tasks which could otherwise be easily handled by support staff. Rather than allowing these tasks to become a significant drain on group energy, a leader to utilize volunteer resources from the community, host agency, and eventually the group members themselves, as discussed previously.

4. NEW MEMBERS. In open-membership groups, the advent and exit of members can be particularly difficult for remaining participants to deal with. For example, old members may resent having to go back over old territory, while new members may be overwhelmed by the intensity of sharing among the old members. However, periodically going back over such basic issues as the goals and norms of the group can facilitate discussion among even the old members of how exactly those objectives are to be operationalized. Also, such discussions provide an opportunity for members to evaluate ways in which the group has changed since its inception, and how they have benefited from their participation. Integration of new members can be facilitated by actively screening and briefing potential new members, and also by pairing new members with existing core members, who then have primary responsibility for orienting the initiates into the group. Such orientation can occur at a time convenient to them both, whether before or after the meeting, during a break, at one of their homes, etc.

5. SOCIAL FUNCTIONS. Many support groups decide to have periodic social gatherings aside from the normal group meetings. These may take the form of holiday celebrations, picnics, outings, etc. Among the issues to be addressed is whether to include the impaired patient and/or other family members, or whether to limit it only to group members. Another issue is whether to include former ("retired") group members or not. There is no set rule on these questions, and they should be decided through the discussions of the group members.

6. CONTROLLING MEMBERS. Often, one or more members will assume patriarchal or matriarchal roles within the group hierarchy, out of a need to be in control and be seen as experts. Although such individuals may weel have much knowledge to share with other group members, such controlling behavior is usually a ploy to avoid dealing with their own conflicted feelings about caregiving. Generally, the best response is to help such individuals get the attention and support they crave without depending on inappropriate controlling behaviors to achieve this. This can be done by expressing appreciation their obvious concern for the welfare of the group, while empathizing with how hard it can be to have so much responsibility. Rather than simply displacing them from their assumed positions, it is less threatening to them and the group to assist them to take the role of experts, but only within clearly-defined and appropriate boundaries. Often, having clear limits will relieve the group's concern regarding monopolization of the group experience by one or two participants, while also relieving those individuals of some of the anxiety which prompts their need to appear in control.

7. SOCIAL ACTION. In addition to helping their members take constructive action on their own behalf and for the benefit of one another, some support groups concern themselves with larger-scale social change, as well. Faced with problems which are inherently insoluble, participants can find a sense of purpose and effectance in promoting significant change in some of the societal conditions which underly the stressfulness

of the situations with which they are faced. For example, support groups have utilized political advocacy to induce legislators to provide tax credits and financial reimbursement for caregivers, and have assisted local organizations to develop and implement additional services such as respite care and homemaker services. Such advocacy by group members inevitably brings them into contact with other caregivers, fostering increased mutual support and helping caregivers to feel less guilty and about their concerns. Moreover, their concerns can be seen as legitimate, and deserving of community support and relief rather than the stigmatization which they so often feel. In this way, support groups can assist their members to achieve personal and group goals related to increased feelings of competence and effectiveness in the caregiving role.